Social Media as a Tool for Understanding the Role of Motor Differences in Neurodivergent Identity and Lived Experience

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Social media offers an exciting opportunity for the field of motor development and behavior research. With platforms such as Twitter offering access to historical data from users’ public bios and posts, there is untapped potential to examine community perspectives on the role of motor differences in identity and lived experience. Analysis of online discourse offers advantages over traditional qualitative methods like structured interviews or focus groups, including a less-contrived setting, global geographic and cultural representation, and ease of sampling. The aim of this special section is to present a pipeline for harvesting and analysis of Twitter data related to users’ identities and discourse characteristics, specifically situated in the context of motor development and behavior. This pipeline is demonstrated in two independent studies, one on autistic users and one on developmental coordination disorder (DCD)/dyspraxic users. These studies demonstrate the utility of Twitter data for research on neurodivergent and disabled people’s perspectives on their motor differences, and whether they are expressed as part of their identity. Implications of results are discussed for each study, as well as in the larger context of future research using a variety of approaches to analysis of social media data, including those from predominantly image- and video-based platforms.

Keywords: autism, Twitter, developmental coordination disorder, dyspraxia

Researchers have long known that motor differences (i.e., motor features that may or may not cause problems or disability) in neurodivergent individuals persist into adulthood, but their effect on adults’ daily living experiences has not been adequately characterized. The initial idea for the projects included in this special section grew out of a sense that adults’ accounts of lived experiences had too long been eclipsed by those of others (e.g., caregivers, clinicians, educators) in the literature. We grappled with the best means of amplifying neurodivergent adults’ voices in order to better understand the functional impact of their motor differences.

While focus groups and interviews have long been used to gather information on community perceptions, experiences, and needs, social media has increasingly
been leveraged as a means of gathering data from a larger and more diverse sample. Yet, the field of motor development and behavior research has lagged behind in this regard, continuing to rely heavily on lab-based studies and traditional methods for data collection. Our use of social media has largely (though not exclusively) been constrained to recruitment, dissemination, and survey-based research.

Laying the Groundwork for a Pipeline

In March 2020, the world of motor development and behavior research was turned upside down by the COVID-19 pandemic. Many researchers who had long relied on lab-based studies were challenged to embrace digital methods for data collection. We, like others, were left searching for an accessible, valid means of collecting and analyzing motor data acquired remotely. This search led us to social media, where an abundance of such data is publicly available in the natural discourse of neurodivergent adolescents and adults. Some of this discourse is prompted, as in the case of moderated discussion threads, and some is spontaneous. In either case, we can learn a lot from listening to the ways that neurodivergent people talk about their motor differences, and from learning how they perceive these characteristics in relation to their identities, goals, and access needs.

Although the social media platform Twitter has made archived data available to academic researchers since 2006, prior studies using these data have centered predominantly on sociopolitical issues. There was not an established best-practice pipeline for motor development and behavior researchers wishing to tap into this extensive resource, nor a sense of how useful the data might be for answering questions regarding motor development and behavior.

Our aim in this special section is to introduce such a pipeline as a starting point for discussions in the fields of motor development and behavior research and/or neurodivergence research that can lead to establishment of a unified methodology. Here, we provide a tutorial designed to be accessible to researchers with limited prior coding experience, including sample code and examples of results obtained using this approach (Fears et al., 2023 in this special section). We then demonstrate the use of this pipeline in two mixed-methods studies assessing motor-related themes in the bioinformation and tweet contents of autistic (Chatterjee et al., 2023 in this special section) and developmental coordination disorder/dyspraxic (Tamplain et al., 2023 in this special section) Twitter users.

The results of these studies underscore the significant lifelong impact of motor differences on individuals’ daily lives. They highlight the need for researchers and clinicians to prioritize studies of adults’ perspectives in order to improve access to appropriate supports and accommodations. They raise new questions about variability in the degree to which neurodivergent people integrate their motor differences into their identities, and what role clinical and community awareness may play in whether people use a particular term to self-identify.

Most importantly, these studies provide converging evidence that there is meaningful, valuable information to be gained from self-advocates’ perspectives on their motor differences via analysis of social media data. They offer a jumping-off point from which to build best-practice pipelines for analysis of social media
data and highlight some of the particular considerations relevant to the field of motor development and behavior.

Forging Ahead . . .

Since the inception of this work and submission of this special section, Twitter returned to operation as a private company purchased by Elon Musk on October 27th, 2022. As of April 20th, 2023, the Academic Research Access category for the Twitter application programming interface (API) has been replaced with a new set of access tiers available to all individuals. Currently, the methods in this special section work as described once a researcher has obtained access to the API, though creating an account to request access may differ. Researchers should refer to Twitter’s Developer Platform for the most up-to-date process for gaining access to historical data. As with any external resource, it is possible that access procedures will change over time.

Other social media platforms may also offer a promising avenue for future research, including those with predominantly image- or video-based content (e.g., Instagram, TikTok, YouTube). Content analysis of the imagery that users choose to accompany text may reveal new information about how neurodivergent and/or disabled people experience and identify with motor differences in daily living, or help to further contextualize the results presented in these studies. The strengths and limitations of text versus image-based data analysis are discussed further in Fears et al. in this special section.

The field will benefit from open science practices like preregistration and sharing of annotated code as we explore the use of new platforms (e.g., Instagram, TikTok), develop methods for processing more challenging data types (e.g., images, videos), and grapple with the complexity of multimodal data analysis (e.g., concurrent analysis of text, image, and reaction data from a single post or thread).

Honoring Users’ Privacy and Identities Through Language Choices

Throughout this special section, we paraphrase and refer to themes rather than using direct quotes, so that users’ tweets are not subject to greater publicity than they may have reasonably expected, in keeping with best-practice guidelines for use of Twitter data in research (Williams et al., 2017). For this reason, content referenced in this manuscript is not attributed to individual users. Instead, we offer our gratitude to the entire #ActuallyAutistic and #developmental coordination disorder/dyspraxic community on Twitter for the opportunity to learn from their perspectives.

Out of respect for preferences expressed by many autistic self-advocates in our studies, in the literature (Bottema-Beutel et al., 2021; Botha et al., 2021) and in the community, we have chosen to use identity-first (rather than person-first) language throughout this special section when referring to autistic people. We also use identity-first language when referring generally to disabled people, in keeping with community-driven guidance. The developmental coordination disorder/dyspraxia community has not yet established best-practice guidance for language in the
literature or expressed strong preferences in our studies, and so for consistency, we have chosen to use identity-first language when referring to this group as well. In doing so, it is not our intention to diminish or invalidate the preferences or perspectives of those who prefer person-first language. We recognize that identity is deeply personal and affirm that all individual preferences regarding the language used to express one’s own identity are valid and should be respected.

We also use the term “motor differences” to describe features that may or may not cause problems or disability, depending on a person’s goals, context, and access to appropriate supports or accommodations. We continue to welcome feedback on ways that we can effectively partner with the community to advocate for respect, acceptance, inclusion, and representation in research.

Conclusion

We hope that readers will find this special section useful in considering whether to use social media data for their own research, and informative as a snapshot of neurodivergent and disabled people’s perspectives on the role of motor differences in their identities and lived experiences. This is a starting point for planned future studies delving into more complex questions about motor ability and identity. We encourage others to further refine the pipeline we introduce here, with the goal of establishing a unified yet flexible approach that can be adopted by researchers across the field of motor development.

Note

1. The term “neurodivergent” is used to describe all brains that diverge from typical. This is a term of inclusion that applies to a wide range of populations, including people with neurodevelopmental conditions, brain injuries, and psychological conditions. The term is attributed to Kassiane Asasumasu, a multiply neurodivergent self-advocate who first proposed the term in the early 2000s (the first documented record that we are aware of is a 2015 Tumblr post). It is related to but distinct from the concept of “neurodiversity,” which posits that no two brains are identical. The concept of “neurodiversity” emerged from within the community and was first used in academic publication by Australian sociologist Judy Singer in 1998.

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References


